

# Union Calendar No. 377

111<sup>TH</sup> CONGRESS  
2D SESSION

# H. R. 1230

[Report No. 111-637]

To amend the Public Health Service Act to provide for the establishment of a National Acquired Bone Marrow Failure Disease Registry, to authorize research on acquired bone marrow failure diseases, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 26, 2009

Ms. MATSUI (for herself, Mr. BISHOP of Georgia, Mr. MURTHA, Mr. McDERMOTT, Mrs. EMERSON, Mr. GENE GREEN of Texas, Mr. ABERCROMBIE, Ms. SCHWARTZ, Mr. CONYERS, Ms. HIRONO, Ms. BORDALLO, Mr. LEWIS of Georgia, Mr. FRANK of Massachusetts, Mr. WOLF, Mr. KING of New York, Mr. VAN HOLLEN, Mr. McGOVERN, Ms. DeGETTE, Mr. ARCURI, and Ms. ESHOO) introduced the following bill; which was referred to the Committee on Energy and Commerce

SEPTEMBER 28, 2010

Additional sponsors: Mr. HONDA, Mr. PLATTS, Mr. BURGESS, Mr. GONZALEZ, Mr. BISHOP of New York, Mr. SESTAK, Mr. ALTMIRE, Ms. BALDWIN, Mr. MURPHY of Connecticut, Mr. BARROW, Mr. ENGEL, Mr. STARK, Mr. HINCHEY, Mrs. MILLER of Michigan, Mr. BRALEY of Iowa, Ms. SCHAKOWSKY, Mr. McCOTTER, Mr. BUTTERFIELD, Mr. SNYDER, Mr. CLAY, Mr. ELLSWORTH, Mr. CARNAHAN, Mr. CLEAVER, Mrs. BONO MACK, Mr. MAFFEI, Mr. LATHAM, Mr. LOEBSACK, Mr. COHEN, Mr. ELLISON, Ms. FUDGE, Mr. CHANDLER, Mr. TOWNS, Ms. NORTON, Mr. HALL of Texas, Mr. NEAL of Massachusetts, Mr. HILL, Mr. BOUCHER, Mr. FALEOMAVAEGA, Mr. OLIVER, Mr. PITTS, Mr. HASTINGS of Florida, Mr. HOLDEN, and Mrs. CHRISTENSEN

SEPTEMBER 28, 2010

Reported with amendments, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in *italic*]

[For text of introduced bill, see copy of bill as introduced on February 26, 2009]

# **A BILL**

To amend the Public Health Service Act to provide for the establishment of a National Acquired Bone Marrow Failure Disease Registry, to authorize research on acquired bone marrow failure diseases, and for other purposes.

1       *Be it enacted by the Senate and House of Representa-*  
2       *tives of the United States of America in Congress assembled,*

3       **SECTION 1. SHORT TITLE.**

4       *This Act may be cited as the “Acquired Bone Marrow*  
5       *Failure Disease Research and Treatment Act of 2010”.*

6       **SEC. 2. ACQUIRED BONE MARROW FAILURE DISEASE RE-**  
7               **SEARCH.**

8       *Part B of title III of the Public Health Service Act*  
9       *(42 U.S.C. 243 et seq.) is amended by inserting after section*  
10      *317T the following:*

11      **“SEC. 317U. ACQUIRED BONE MARROW FAILURE DISEASE**  
12               **RESEARCH.**

13           *“(a) IN GENERAL.—The Secretary may conduct re-*  
14      *search on acquired bone marrow failure diseases. Such re-*  
15      *search may address factors including—*

16           *“(1) trends in the characteristics of individuals*  
17      *who are diagnosed with acquired bone marrow failure*  
18      *diseases, including age, race and ethnicity, general ge-*  
19      *ographic location, sex, family history, and any other*  
20      *characteristics determined appropriate by the Sec-*  
21      *retary;*

22           *“(2) the genetic and environmental factors, in-*  
23      *cluding exposure to toxins, that may be associated*  
24      *with developing acquired bone marrow failure dis-*  
25      *eases;*

1           “(3) approaches to treating acquired bone mar-  
2       row failure diseases;

3           “(4) outcomes for individuals treated for ac-  
4       quired bone marrow failure diseases, including out-  
5       comes for recipients of stem cell therapeutic products;  
6       and

7           “(5) any other factors pertaining to acquired  
8       bone marrow failure diseases determined appropriate  
9       by the Secretary.

10       “(b) *COLLABORATION WITH THE RADIATION INJURY*  
11 *TREATMENT NETWORK.*—In carrying out subsection (a),  
12 the Secretary may collaborate with the Radiation Injury  
13 Treatment Network of the C.W. Bill Young Cell Transplan-  
14 tation Program established pursuant to section 379 to—

15           “(1) augment data for the studies under such  
16       subsection;

17           “(2) access technical assistance that may be pro-  
18       vided by the Radiation Injury Treatment Network; or

19           “(3) perform joint research projects.

20       “(c) *DEFINITION.*—In this section, the term ‘acquired  
21 bone marrow failure disease’ means—

22           “(1) myelodysplastic syndromes (MDS);

23           “(2) aplastic anemia;

24           “(3) paroxysmal nocturnal hemoglobinuria  
25       (PNH);

- 1           “(4) pure red cell aplasia;  
 2           “(5) acute myeloid leukemia that has progressed  
 3       *from myelodysplastic syndromes;*  
 4           “(6) large granular lymphocytic leukemia; or  
 5           “(7) any other bone marrow failure disease spec-  
 6       *ified by the Secretary, to the extent such disease is ac-*  
 7       *quired and not inherited, as determined by the Sec-*  
 8       *retary.”.*

9   **SEC. 3. MINORITY-FOCUSED PROGRAMS ON ACQUIRED**  
 10       **BONE MARROW FAILURE DISEASES.**

11       *Title XVII of the Public Health Service Act (42 U.S.C.*  
 12       *300u et seq.) is amended by inserting after section 1707A*  
 13       *the following:*

14   **“SEC. 1707B. MINORITY-FOCUSED PROGRAMS ON ACQUIRED**  
 15       **BONE MARROW FAILURE DISEASES.**

16       “(a) *INFORMATION AND REFERRAL SERVICES.—*

17           “(1) *IN GENERAL.—The Secretary may establish*  
 18       *and coordinate outreach and informational programs*  
 19       *targeted to minority populations, including Hispanic,*  
 20       *Asian-American, Native Hawaiian, and Pacific Is-*  
 21       *lander populations, that are affected by acquired bone*  
 22       *marrow failure diseases.*

23           “(2) *PROGRAM ACTIVITIES.—Programs under*  
 24       *subsection (a) may carry out activities that include—*

1           “(A) making information about treatment  
2           options and clinical trials for acquired bone  
3           marrow failure diseases publicly available; and

4           “(B) providing referral services for treat-  
5           ment options and clinical trials.

6           “(b) *DEFINITION.*—In this section, the term ‘acquired  
7           bone marrow failure disease’ has the meaning given such  
8           term in section 317U(c).”.

9           **SEC. 4. BEST PRACTICES FOR DIAGNOSIS OF AND CARE FOR**  
10                           **INDIVIDUALS WITH ACQUIRED BONE MAR-**  
11                           **ROW FAILURE DISEASES.**

12           *Part B of title III of the Public Health Service Act*  
13           *(42 U.S.C. 243 et seq.), as amended by section 2, is further*  
14           *amended by inserting after section 317U the following:*

15           **“SEC. 317V. BEST PRACTICES FOR DIAGNOSIS OF AND CARE**  
16                           **FOR INDIVIDUALS WITH ACQUIRED BONE**  
17                           **MARROW FAILURE DISEASES.**

18           “(a) *GRANTS.*—The Secretary, acting through the Di-  
19           rector of the Agency for Healthcare Research and Quality,  
20           may award grants to researchers to study best practices  
21           with respect to diagnosing acquired bone marrow failure  
22           diseases and providing care to individuals with such dis-  
23           eases.

1       “(b) *DEFINITION.*—*In this section, the term ‘acquired*  
2 *bone marrow failure disease’ has the meaning given such*  
3 *term in section 317U(c).’.*”

Amend the title so as to read: “A bill to amend the Public Health Service Act to provide for research on acquired bone marrow failure diseases, minority-focused programs on such diseases, and the development of best practices for diagnosis of and care for individuals with such diseases.”.

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11<sup>TH</sup> CONGRESS  
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